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**“We all talk about it as though we’re thinking about the same thing.” Healthcare professionals’ goals in the management of pain due to advanced cancer: a qualitative study.**

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List of tables: table 1 (as separate file).

**Abstract**

**Purpose:** Unfortunately several barriers impede successful management of cancer pain including those relating to the assessment and measurement of pain. There is currently no consensus as to what constitutes good pain control or what healthcare professionals are aiming to achieve in the management of pain for patients with advanced cancer. This study aimed to explore healthcare professionals' views and experiences to elicit what they are aiming to achieve in managing pain for patients with advanced cancer.

**Methods:** Healthcare professionals involved in the management of cancer pain were sampled purposively and interviewed using a semi-structured interview technique until saturation of data. Data were analysed using the constant comparison approach.

**Results:** Sixteen interviews took place and four main themes emerged: aims of pain management, assessing response to pain management, managing expectations, and building relationships. Healthcare professionals found assessing patients' pain challenging and reported that patients had difficulty using numerical rating scales. Healthcare professionals used different terms when talking about managing pain, such as 'pain control', but found it difficult to define these terms. Maintaining patients' function and managing their expectations was described as important. However, it was not always clear whether the patient goals mentioned were voiced explicitly by the patient, or assumed by the healthcare professional.

**Conclusion:** Healthcare professionals described what they deemed important in the management of pain. The goals they mentioned almost exclusively related to function as opposed to pain scores, but patients' goals and expectations were often not elicited specifically.

**Keywords:** cancer, pain, goals, healthcare professionals

**Word count 3495 not including abstract / acknowledgements / references**

## Introduction

Despite the widespread use of the World Health Organisation analgesic ladder, there is evidence to suggest that cancer pain continues to be a problem for many patients [1, 2]. For example, a systematic review found that in patients with advanced cancer, the prevalence of pain was 64% with more than one third of patients rating their pain as moderate or severe [2]. Unrelieved pain affects patients' function, well-being, sleep and mood [1], as well as having an impact on family caregivers [3]. Patient-related barriers to relief of pain are described in the literature [4-10]; those related to healthcare professionals include fears of tolerance, addiction, and lack of knowledge relating to prescribing opioids [4-6, 8, 9, 11-13].

Although several researchers have explored the relationship between healthcare professionals' knowledge and attitudes, and their willingness to prescribe appropriate analgesics [4, 9, 11-13], few have considered what healthcare professionals' overall aims/goals of pain management are and how they determine when pain is 'controlled'. Rankin and Snider studied the practice of nurses caring for patients with cancer pain; 58% felt the goal of administering opioids was to reduce pain rather than relieve it entirely [14]. Green et al suggested healthcare professionals' goals may be important in determining the level of pain relief achieved for individual patients [15]. A recent study conducted by the authors exploring the priorities of patients with advanced incurable cancer about the management of their pain, revealed they prioritized their function over complete control of pain and set 'goals', for themselves such as achieving everyday tasks or hobbies. However, these goals were not communicated openly to their healthcare professionals [16]. Following on from this work and in view of the paucity of research examining healthcare professionals' goals in managing pain, we performed this study.

## Aims

We aimed to explore the views and experiences of healthcare professionals to elicit what they are aiming to achieve in managing pain for patients with advanced cancer.

## Methods

We performed a qualitative study with a purposive sample of healthcare professionals managing patients with pain due to advanced cancer. To capture a range of experiences and specialties, oncologists, palliative care physicians and palliative care nurse specialists from acute hospital and hospice care settings in a major UK city were invited to interview by letter. Following informed consent, face-to-face interviews were performed using a topic guide (Table 1) by one researcher (RB) and transcribed verbatim. Interviews lasted between 30 and 70 minutes.

Data were analysed using the constant comparison method, derived from the principles of Grounded Theory [17]. Analysis was carried out (by RB) as soon as transcripts were available to identify codes and emerging themes, in order to allow a constant cycle between the development of hypotheses from the data and further exploration of these through subsequent interviewing. A second researcher (CR) read the transcripts independently to verify the codes. CR and RB first met after 3 transcripts were analysed to compare codes and then again after every few interviews. Early codes were discussed and discarded following analysis of new transcripts. All 16 transcripts were eventually read in their entirety and analysed and discussed repeatedly in order to check codes, refine categories, and to gather these into the final themes. In practice there were no disputes, but a third researcher was available to consult should this have been the case.

Data saturation was achieved after 13 interviews but a further 3 were carried out to confirm this. Analysis of early transcripts, particularly those interviews with the oncologists led to more oncologists being interviewed than was originally planned in order to fully explore their role in pain management (see results). The topic guide did not need to be changed.

Ethical approval was gained from the local research ethics committee (LREC ID: O7/H0106/151).

## Results

Eighteen health care professionals were invited to take part and 16 agreed. Five oncologists (four consultants and one specialist trainee), five palliative care clinicians (three consultants and two specialist trainees), and six non-prescribing specialist palliative care nurses (three based in hospital liaison teams and three in the community) were interviewed. Care settings that the healthcare professionals worked in included an oncology centre, two teaching hospitals, a specialist palliative care unit, a hospice, and a hospice-based community team. Four distinct but related themes emerged from the data; aims of pain management, assessing response to pain management, managing expectations and building relationships.

### Aims of pain management

Healthcare professionals used different terms when talking about managing pain, such as 'pain control' and 'pain management', but found it difficult to define these terms specifically. Definitions ranged from patients being pain-free, pain not interfering with patients' lives, pain not affecting mood and function and patients not needing to take many breakthrough doses of analgesics.

*Well yeah, although we have an increasing understanding of pain and its treatment, there's no firm belief about how pain control should be managed and what pain control is ... It's a term that we use, but I think if you ask ten different people to write it down it would mean different things to different people. Yet we all talk about it as though we're thinking about the same thing.*

*Hospital specialist nurse 2*

Despite the lack of consensus regarding a definition of pain control, healthcare professionals reported the following as important: maintaining function, providing an explanation of the pain and what the professional was trying to achieve, formulating a plan, achieving a good night's sleep, and having something effective for the patient to take if the pain got severe.

*To try and alleviate somebody's symptoms to a degree that they find acceptable ... so that they are able to function at a level that they want to.*

*Palliative medicine consultant 3*

Perhaps surprisingly, only five of the healthcare professionals interviewed aimed to get people pain free. All five of these were quick to add that this was sometimes not possible, and three were clear that they would not share this goal with patients; they did not want to set up unachievable expectations.

*I think certainly my aim now is to get the patient as comfortable as possible and as pain-free as possible ... But there are some patients, from experience I know, that it has been very difficult to control pain, and it may not be achievable ... I don't ever walk in and say, "I'm going to stop your pain."*

*Hospital specialist nurse 3*

*For me, the ultimate goal ... is for that person to be pain-free at rest and on movement, with no side effects ... And I don't tell them that, because ... starting with a goal that may not be realistic. But that would be the goal in my head.*

*Hospital specialist nurse 3*

The impact of side effects was discussed by almost all of the healthcare professionals who saw this as limiting how much improvement in pain could be achieved. This was more important in those with pain perceived to be 'difficult' (e.g. incident or neuropathic pain were mentioned).

*Because I think really to get people pain-free, it concerns me, because I think we probably teeter on being a little bit opiate toxic, and then that can have other side effects and the quality of life goes down.*

*Community specialist nurse 2*

Whilst healthcare professionals talked about managing patients' pain, the oncologists interviewed did not see their role as key. They stated they saw patients less frequently than some other healthcare professionals and that this limited their involvement in ongoing pain management, necessitating handing overall responsibility for pain control to the GP and/or palliative care team:

*I want to know about their pain, but I won't necessarily delve in and get too much into the management, because I don't feel that ... we're necessarily in the best position to then change things, and then monitor that change as frequently and as consistently as perhaps people in the community can be.*

*Oncology consultant 4*

The majority of healthcare professionals felt patients' expectations and wishes regarding pain management were important. However, it was not always clear whether the patient goals mentioned were voiced explicitly by the patient, or assumed by the healthcare professional:

*Interviewer: Do you specifically seek out what they [the patients] are hoping you'll do or ... ?*

*Community specialist nurse 1: Sometimes yeah. Not maybe ... not maybe consciously, you know, not in the way you do say when you're talking about admitting somebody, what you're trying to achieve, but yeah maybe.*

*Community specialist nurse 1*



*I always presume it's important for them to be out of pain or be able to deal with their pain or um it not being affecting them too much.*

*Oncology specialist trainee*

*I suppose they're hoping that we're going to get rid of their pain.*

*Hospital specialist nurse 1*

### **Assessing response to pain management**

In spite of using a range of strategies to assess pain, healthcare professionals found judging response to treatment challenging. This related to difficulties patients had in describing pain and using numerical rating scales. Because of this, the majority of healthcare professionals reported using such scales only occasionally in their practice.

*And you say to people, "Describe your pain," and they go, "Oh," but they look at you blankly, "What do you mean describe it? It's just a pain, it's just there. I don't know what you mean."*

*Community nurse specialist 3*

*A significant proportion of patients cannot score pain, um even if you give them that scale ... they just say it's very bad.*

*Oncology consultant 1*

*But my experience of the whole 0-10 isn't that great. ... Actually they go, "What?" like and I'm not sure it helps any more than saying, "Does Oramorph help your pain?"*

*Community nurse specialist 1*

### Managing expectations

Modification of expectations was seen as important by the majority of healthcare professionals in terms of setting up and protecting an honest, trusting relationship with the patient and to ensure patients weren't 'let down' if pain was not relieved as much as they were hoping it would be. Modification of expectations was also seen by the palliative care doctors as vital for them not being "set up to fail".

*I think if you set yourself up to fail you also set yourself up to ... to damage what could be a developing trust and a developing depth of communication in your relationship with the patient.*

*Palliative medicine consultant 1*

As well as protecting patients, three healthcare professionals acknowledged that modifying expectations could be protective of themselves also, with one suggesting that modifying expectations might help the healthcare professional more than the patients:

*I think sometimes ...you change your goals and you shift people's ideas insidiously, and sometimes that's not helpful ... Yeah ... but sometimes I have to think, "Is that because that helps me or is that because it helps them?"... I would like to think it helps them. But as an inevitable part of anyone's job, you'd like to have some job satisfaction ... it's nice to have little goals or little objectives that you can tick off yourself.*

*Palliative medicine specialist trainee 1*

Six healthcare professionals reported being explicit with patients with 'difficult' pain about what they felt was achievable in the management of their pain during their initial consultation.

*There are people, particularly with very much movement related pain or nerve pain, where actually we get there but they end up with difficult side effects.*

*And I think they're the ones, when you meet them the first time and they're kind of ... I've really learnt not to say, I've never, never said, "Oh yeah I'm going to make you have no pain," but I'm quite guarded in what I say.*

*Community specialist nurse 1*

Four healthcare professionals described helping patients to refocus their goals and how they achieved them:

*Um but something like, you know, being able to cuddle the child, then actually I would work on, "Right (a) what can we do for the pain and (b) how can we achieve a compromise?" You know, the compromise where the mum sits on the settee and the child scrambles over the arm.*

*Palliative medicine consultant 1*

### **Building Relationships**

The majority of healthcare professionals appeared patient-centred and talked about the relationship with the patient as a partnership. Frequently they tried to find ways to empower patients in the management of their pain. However, this sometimes led to the healthcare professionals not increasing analgesics as much as they might have done otherwise, in an attempt to balance being patient-centred and building up a relationship in the overall context of achieving 'pain control'.

*I don't feel there's any rush to get somewhere, you know, unless it's really necessary. And again I don't want to be seen as the nurse that comes to the door ... and just starts giving them tablets and tablets, you know, I'd rather build a relationship.*

*Community specialist nurse 3*

Overall there was an assumption that being patient centred was more important than achieving pain control at any cost:

*So although his pain control, I wouldn't say is good, he's saying it's fine. So, you know, so ... we're just leaving things at the moment ... So it's trying to be sort of patient focused really and thinking what's important for them.*

*Community specialist nurse 2*

## Discussion

This is the first study we are aware of to explore healthcare professionals' aims in the management of pain due to advanced cancer. Healthcare professionals talked about what they perceived to be important in the management of pain for their patients and themselves. However, healthcare professionals appeared to assume what patients' goals and expectations were, rather than clearly identifying them with patients. The goals mentioned related almost exclusively to function, and managing expectations was viewed as integral to the management of pain for healthcare professionals. Despite the differing roles of those interviewed, the goals held by the healthcare professionals were remarkably similar across the groups. However, there were two main exceptions: firstly, the oncologists did not consider themselves to be the lead clinician in a patient's pain management, and secondly, palliative care physicians were concerned not to 'fail' their patients.

Despite healthcare professionals using the terms 'pain control' or 'pain management', there was no consensus on how these terms were defined. Healthcare professionals had several goals in managing pain, with maintaining function and balancing pain relief against side effects as priorities for most. However, aims did vary. For a minority their ultimate goal was to render patients pain free; but these healthcare professionals did not share this goal with the patient, for fear of letting them down if this proved unachievable. Other healthcare professionals were more circumspect and felt that getting rid of pain without causing significant side effects was not possible, thus achieving some pain relief without intolerable side effects was the best that could be hoped for, particularly in those with 'difficult' pain. This lack of consensus regarding definitions of 'pain control' is

echoed in the literature. In pain research the effectiveness of an analgesic is accepted as clinically significant if patients achieve a two point reduction on an 11-point pain intensity scale [18, 19]. Serlin established a worst pain score of five or greater on an 11 point scale as 'uncontrolled pain', due to its interference with function [20]. However, in clinical practice there appears to be no such agreement on what might represent 'pain control'. Zelman et al reported how patients described 'acceptable, manageable and tolerable days' in terms of strategic use of pain medication, but this was not specific to pain due to advanced cancer [21]. Current guidelines on pain management in cancer do not define the terms used (e.g. pain relief) and do not refer to overall goals beyond reference to a 'sequence of aims' [22, 23].

Healthcare professionals discussed their challenges in assessing pain and subsequently assessing response to interventions. They felt patients found it difficult to describe their pain or use numerical rating scales despite guidance suggesting routine use [23]. This may be because such scales are designed primarily as research tools and patients are seldom involved in their development [24, 25]. This corresponds with the findings of our recent qualitative study in patients with advanced cancer; patients found the use of numerical rating scales challenging and did not equate 'pain control' with being pain-free, or having a score at a certain level. Instead patients described the ability to perform tasks and functions as important in determining whether their pain was 'controlled' or not. These patients reported not discussing these goals openly with healthcare professionals [16]. Thus patients seem clear about what they want from the management of their pain which appears to be congruent with what healthcare professionals are trying to achieve; but these goals do not appear to be discussed openly between patients and their healthcare professionals despite the healthcare professionals discussing the need to modify expectations. This is in contrast to many chronic pain settings, where goal setting is a commonly used tool [26]. The effectiveness of goal setting as an isolated intervention has not been widely studied, but goal setting and goal review were

valued highly by patients taking part in the NHS Expert Patient Programme [27]. Little is known about goal setting in patients with advanced cancer.

Brennan suggests that one of the ways healthcare professionals can make patients with cancer feel secure is by giving clear clinical goals to aim for [28]. Good goals need to be attainable [29], and being able to be flexible and adjust goals can protect against depression [30] and maintain hope [31]. Indeed, Gum and Snyder [32] have defined hope as 'positive expectations for goal attainment'. Specifically identifying goals would enable the identification of realistic aims and allow negotiation of expectations and goals to be done transparently from a shared starting point. Mourning the loss of unattainable goals may also be allowed for, a process seen as an important part in upholding hope [32]. Finally, goal setting can assist healthcare professionals in seeing the 'whole' patient [33] very much in sympathy with the philosophy underpinning palliative care.

The lack of open discussion about goals of pain management is not dissimilar to other communication issues in cancer such as discussion of prognosis [34, 35]. It is possible that, similar to prognostic information [35, 36], patients will have varying needs for information about their goals of pain management.

Healthcare professionals described the importance of the therapeutic relationship in the management of pain. Patient-centred care has been demonstrated to increase patient satisfaction [37-39] and is widely promoted as the best approach for health care professionals to take [40]. There was a suggestion that maintaining a good relationship and being patient centred had a higher priority than achieving pain control in itself, perhaps because almost all of the healthcare professionals saw empowering patients as crucial in managing pain.

## **Limitations**

Only healthcare professionals involved in managing pain due to advanced cancer on a frequent basis in one UK city were interviewed. Although we do not intend our findings to be generalisable, they may be transferable to similar healthcare professionals and settings. RB is a palliative care clinician involved in managing pain due to advanced cancer. It is possible her clinical role may have affected the interviews in terms of healthcare professionals being less open and honest, for example they may have modified their responses in an attempt to seek approval. However, as the healthcare professionals were forthcoming in discussing elements they found challenging as well as mistakes made, this seems unlikely.

### **Conclusion and implications for clinical practice and research**

The participants in this study were experienced in the management of pain due to advanced cancer, yet they struggled to define what they mean by pain control. The aims of different healthcare professionals were variable (with only a minority aiming to get patients pain-free) but they appeared to agree that the overall goals of pain management were related to function. However, healthcare professionals appeared to assume what patients' goals and expectations were, rather than clearly identifying them with patients. Discussing these explicitly might allow moderation of expectations which was viewed by the healthcare professionals as integral to the management of pain.

Number rating scales were not perceived to be helpful in defining control of pain. Involving patients in the development of tools specifically designed to assess the control of pain in cancer in the clinical setting may be of benefit. Patient-centred, jointly derived outcomes for pain might be a way of directing treatment, maintaining patients' sense of identity and role (which we know is important to them[41, 42]), and protecting patients and healthcare professionals from unrealistic expectations. These could be considered as a tool for measuring patient outcomes in the palliative care setting, but further research in these areas would be needed.

The oncologists in our study found it challenging to manage pain in clinic due to infrequent follow up. Joint clinics with palliative care might help this and non-oncologists should not assume that pain management can be tackled in an oncology clinic.

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CR proposed the idea for the study. RB, JG and CR designed the study. JG wrote the protocol and gained ethical approval (with supervision from KF). RB carried out the interviews. RB and CR analysed the data. RB wrote the first draft of the paper. All authors contributed to the writing of the final version RB received a grant from the Association of Palliative Medicine, which covered transcribing costs. None of the authors has any conflicting interests.

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